

DISTRICT OF COLUMBIA
MENTAL RETARDATION AND DEVELOPMENTAL
DISABILITIES
FATALITY REVIEW COMMITTEE

2006 ANNUAL REPORT



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**DISTRICT OF COLUMBIA
MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES
FATALITY REVIEW COMMITTEE**

2006 ANNUAL REPORT

MISSION:

To reduce the number of preventable deaths of individual with mental retardation and developmental disabilities through identifying, evaluating and improving programs and systems responsible for protecting and serving citizens

PRESENTED TO:

**THE HONORABLE ADRIAN FENTY, MAYOR, DISTRICT OF COLUMBIA
THE COUNCIL OF THE DISTRICT OF COLUMBIA**

DECEMBER 2007

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EXECUTIVE SUMMARY

The District of Columbia Mental Retardation and Developmental Disabilities Fatality Review Committee (hereinafter known as the MRDD FRC or the Committee) is pleased to present the 2006 Annual Report. MRDD FRC was established in February 2001, by Mayor's Order 2001-27 and re-established in September of 2005 by Mayor's Order 2005-143 (see Appendix A). The Committee is charged with examining the events surrounding the deaths of individuals 18 years of age and older who were diagnosed with mental retardation and other developmental disabilities and were wards of the District or receiving supports from the Department of Disability Services (formally the Mental Retardation and Developmental Disabilities Administration) at the time of death.

MRDD FRC is comprised of members who represent public and private community organizations from a broad range of disciplines including health, mental health, education, mental retardation, social services, public safety, legal and law enforcement. These individuals come together as a collective body for the purpose of examining and evaluating relevant facts associated with services and interventions provided to deceased persons diagnosed with intellectual and developmental disabilities.

During the calendar year 2006, 30 persons died who were diagnosed with mental retardation and other disabilities and were served by the DDS. The Committee reviewed 21 cases during the 2006 calendar year. These reviews represented deaths that occurred during calendar years 2002 through 2006. During the fatality review meetings, the MRDD FRC examines an independent investigative report of each individual's death that includes a summary of the forensic autopsy report. The reports highlight each deceased individual's social history, including family and care giver relationships and living conditions prior to death; medical diagnosis and medical history; services provided; and cause and manner of death. Many of the fatality reviews lead to the identification of systemic health care and other service concerns. MRDD FRC makes recommendations to promote comprehensive health care and improve the quality of life for persons diagnosed with intellectual and developmental disabilities.

Recommendations made by the Committee during the period covered by this report (see Appendix B) related primarily to coordination of care, case record documentation and end-of-life issues. The recommendations impact policy, legislative principles, clinical practice, community resources, and city budget allocations.

Summary of Findings for 21 Deaths Reviewed in 2006

- Ninety-five percent of the deaths reviewed were attributed to Natural causes
- Twenty-nine percent of the decedents were over the age of 60 years
- Sixty-seven percent of the decedents died in a hospital setting
- Ninety-five percent of the decedents received an autopsy

Additionally, the 2006 Annual Report provides an ***“Educational Overview on Cerebral Palsy”***. The purpose of Overview is to enlighten the reader on one of the major medical conditions/disorders that is prevalent in the mental retardation/developmental disabilities population and fatalities reviewed by the MRDD FRC.

INTRODUCTION

The 2006 Annual Report is a summary of the work performed by MRDD FRC. It covers data that is specific to 21 decedents diagnosed with intellectual and developmental disabilities (MRDD) who received services from DDS and whose deaths occurred during calendar years 2002 through 2006. It also provides descriptive statistics of 30 individuals who died during 2006 calendar year and received supports from DDS.

MRDD FRC was established in February 2001, under the auspices of the Office of the Chief Medical Examiner (OCME). It is a multi-disciplinary, multi-agency effort that was established for the purpose of conducting retrospective reviews of relevant service delivery systems and the events that surrounded the deaths of District wards and residents 18 years of age and older who received supports from DDS. One goal of the FRC is to make recommendations to improve care and service delivery to citizens of the District.

Committee membership is broad, representing a range of disciplines, public and private agencies as well as community organizations and individuals. Membership includes representation from health, mental retardation, education, mental health, social services, public safety, legal, and law enforcement areas. These professionals come together for the purpose of examining and evaluating relevant facets associated with services and interventions provided to deceased persons diagnosed with intellectual and other disabilities.

The fatality review process includes examination of relevant policies and statutes, independent investigative reports, and reports of forensic autopsies. This information highlights each deceased individual's social history, including family and care giver relationships, as well as living conditions prior to death; medical diagnosis and history; services provided; and cause and manner of death. These reviews examine compliance with District laws and regulations, agency policies and practices, and recommendations by service providers. Many reviews result in the identification of systemic problems and gaps in services that may impact the consumers' quality of life. The Committee recommends systemic strategies to reduce the number of preventable deaths or improve the quality of life for persons diagnosed with an intellectual or developmental disability who were under the care of DDS.

The District of Columbia Code defines mental retardation as a significantly "sub-average general intellectual level" determined in accordance with standard measurements as recorded in the Manual of Terminology and Classification in Mental Retardation, 1973.¹ DDS's eligibility criteria for identification of persons with mental retardation are:

1. Current cognitive assessment (within 3 years prior to application date) with accepted IQ test scoring 75 or below.
2. Current adaptive assessment (within 3 years prior to application date) showing adaptive functioning in the Mild range or below, or indicating that the individual needs supports in at least 2 out of 10 areas of adaptive living.
3. A cognitive assessment before the age of 18 years showing IQ of 75 or below.

¹ D.C. Official Code §7-1301.03(19) (2001)

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By reviewing the information from each death, the FRC hopes to continue the initiation of necessary changes that foster quality provisions for individuals being served by DDS. An important outgrowth of this process is the recognition of best practices, and recommendations to implement those practices as systemic changes. The FRC understands that the information submitted for review cannot change the circumstances that led to individual deaths, however, the Committee strives to use the information to identify trends, direct training needs, recommend modification of public and private policies in order to address systemic issues and to improve the quality of life for these citizens of the District of Columbia.

TOTAL MORTALITY FINDINGS

An important function of the MRDD FRC involves the analysis and review of DDS consumer deaths to identify significant patterns and trends that may help increase knowledge about risk factors and provide information to help guide system enhancements. The Committee actively collects information pertaining to deaths of individuals diagnosed with intellectual and other disabilities who are served by DDS. The following section provides a general description of the analysis of deaths reviewed by the Committee during the 2006 calendar year.

As Table 1 below illustrates, the total number of persons served by DDS for calendar years 2001 through 2006 ranged from 1,547 to 1,993. The actual number of deaths per year of DDS consumers during this six-year span fluctuated between 26 and 36.² Table 1 also supports the fact that the percentage of DDS clients who have died between 2001 and 2006 has ranged from 1.5 to 2 percent.

Table 1: District of Columbia DDS Population and Deaths 2001 to 2006

Year	Population	Number of Deaths	Percentage
2006	1974	30	1.5%
2005	1993	34	1.7%
2004	1915	36	1.9%
2003	1790	31	1.7%
2002	1703	26	1.5%
2001	1547	32	2%

During calendar year 2006, the MRDD FRC reviewed the deaths of 21 persons diagnosed with intellectual and developmental disabilities whose deaths occurred during the 2002 through 2006 calendar years. Table 2 below summarizes the number of deaths by calendar years, which have been reviewed by the Committee since its inception and those pending review. The total number of cases reviewed, (N=132) spans years 2001-2006.

² Information on the total population for each of the four years was provided by the MRDDA Consumer Information System (MCIS).

Table 2: FRC Cases Pending Review

Year	Number of Deaths By Year N=189	Number Of Cases Reviewed By Year	Number of Cases Pending Review N=57
2006	30	6	24
2005	34	24	10
2004	36	26	10
2003	31	23	8
2002	26	21	5
2001	32	32	0
Total	189	132	57

SUMMARY OF 2006 CASE REVIEW FINDINGS

The information contained in this section will cover the data and findings that resulted from cases reviewed during calendar year 2006 (N=21). Data in these tables also clearly specifies the year of the death although the review occurred during 2006.

AGE/GENDER AND MORTALITY

In calendar year 2006, the FRC reviewed the deaths of 21 persons diagnosed with MRDD who ranged in age from 19 to 86 years. Of the 21 deaths reviewed, twenty-nine percent (N=6) were 61 years of age and older. Thirty-three percent (N=7) were between the ages of 51 through 60 years, and twenty-nine percent (N=6) were ages 41 through 50. There was one decedent in each age category of 31 through 40, and 18 through 20 years. There were no decedents in the 21 through 30-year age range.

Based on a seven year review of MRDD FRC data (2000 through 2006), the largest number of deaths involved individuals 61 years of age and older. Overall, the relationship between mortality and age has continued, since 2000, to support the expected trend of mortality increasing with age. After the age of 50 years, the death rate increases dramatically, in line with the overall population trends. The average age of death for calendar years 2000-2006 was 57 years.

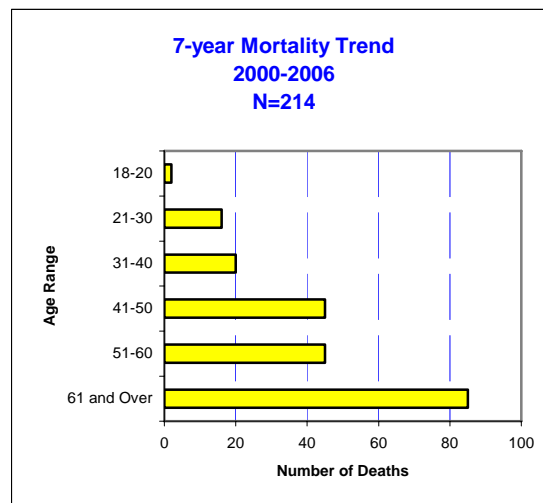


Figure 1: Number of Deaths by Age Range

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Table 3: Decedents by Age Range and Gender of Cases Reviewed (N=21)

Age Range	2002 N=2		2003 N=2		2004 N=1		2005 N=10		2006 N=6	
	Male N=1	Female N=1	Male N=1	Female N=1	Male N=0	Female N=1	Male N=7	Female N=3	Male N=3	Female N=3
18-20	0	0	0	1	0	0	0	0	0	0
21-30	0	0	0	0	0	0	0	0	0	0
31-40	1	0	0	0	0	0	0	0	0	0
41-50	0	1	1	0	0	0	1	2	0	1
51-60	0	0	0	0	0	0	4	0	2	1
61-over	0	0	0	0	0	1	2	1	1	1

Table 3 above depicts the age ranges of the decedents by gender. Fifty-seven percent of the decedents were male (N=12) and forty-three percent were female (N=9).

- Of the 2002 deaths reviewed (N=2), one was a male age 31, and one was a female age 45.
- Of the 2003 deaths reviewed (N=2), one was a male age 50, and one was a female age 19.
- The 2004 decedent (N=1) was a female age 68.
- Of the 2005 decedents (N=10), seven were males who ranged in age from 41 to 86 years, and three were females who ranged in age from 46 to 62 years.
- Of the 2006 deaths (N=6), three were males who ranged in age from 52 to 75, and three were females who ranged in age from 49 to 70.

RACE AND MORTALITY

Table 4: Decedents by Race for Cases Reviewed

Race N=21	2002 N=2		2003 N=2		2004 N=1		2005 N=10		2006 N=6	
	Male N=1	Female N=1	Male N=1	Female N=1	Male N=0	Female N=1	Male N=7	Female N=3	Male N=3	Female N=3
Black	1	1	1	1	0	1	3	3	2	1
White	0	0	0	0	0	0	4	0	1	2

Table 4 above illustrates the race of the 2006 decedents reviewed. Of the deaths reviewed (N=21), fourteen, (67%) were Black and seven (33%) were White. The average age of the Black decedents (N=14) for the 21 cases reviewed was approximately 51 years and the average age of the White decedents (N=7) was approximately 62 years. Overall, the combined average age for the cases reviewed in 2006 (N=21) was 55 years. The following data describes the mean age and race of decedents for each year reviewed during calendar year 2006:

- The average age of the 2002 Black decedents (N=2) was 38 years
- The average age of the 2003 Black decedents (N=2) was 34.5 years.
- The age of the 2004 decedent, a Black female, was 68
- The average age of the 2005 Black decedents (N=6) was 53 years, and the average age of the White decedents (N=4) was 66 years.
- The average age of the 2006 Black decedents (N=3) was 61 years, and the average age of the White decedents (N=3) was 57 years.

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WARD DATA

Ward of residence refers to the decedent's residential address at the time of the death. Addresses include natural homes, foster homes, Intermediate Care Facilities for persons with mental retardation (hereinafter referred as ICF/MR), supervised apartments, group homes, and nursing homes.

Table 5: Ward/Jurisdiction of Residence at Time of Death (N=21)

District Ward/ Jurisdiction District	Deaths Reviewed by Calendar Year N=21				
	2002 N=2	2003 N=2	2004 N=1	2005 N=10	2006 N=6
One	0	1	0	1	0
Two	0	0	0	0	0
Three	0	0	0	0	0
Four	0	0	0	1	1
Five	0	0	0	0	1
Six	1	0	0	3	1
Seven	0	0	1	2	1
Eight	0	0	0	1	0
Maryland	1	1	0	2	1
Virginia	0	0	0	0	1

Table 5 illustrates the decedents' ward or jurisdiction of residence at the time of death by year of death for the total number of cases (N=21) reviewed in 2006. Of the deaths reviewed, 15 decedents resided in the District and six resided in Maryland or Virginia. Of the District residents, the largest numbers of decedents reviewed resided in Wards Six and Seven (N=9).

Decedents Residing in the District of Columbia

- Of the two 2002 decedents, one (50%) lived in Ward Six of the District. This decedent was a 31-year-old Black male who lived in a nursing home.
- Of the two 2003 decedents, one (50%) lived in Ward One of the District. This decedent was a 50-year-old Black male who resided in an ICF/MR.
- The 2004 decedent (N=1) lived in the District. This decedent was a 68-year-old Black female who resided in an ICF/MR in Ward Seven.
- Of the 2005 decedents (N=10), eight (80%) lived in the District, in Wards One, Four, Six, Seven, and Eight. One (12.5%) consumer lived in a nursing home, one (12.5%) lived in their natural home, three (37.5%) resided in a group home setting, and three (37.5%) resided in an ICF/MR. The race of these decedents included six Blacks (75%) and two Whites (25%) with their ages ranging from 41 to 86 years.
- Of the 2006 decedents (N=6), four lived in Wards One, Four, Five, Six, and Seven of the District. Three of the decedents lived in an ICF/MR (75%) and one (25%) lived in a supervised apartment setting. Two of the decedents were Black (50%), and two were White (50%) ranging in age from 59 to 79 years.

Decedents Residing in Out-of State Facilities

- Of the 21 decedents reviewed in this report, six or 28.5% resided in out-of-state facilities. These decedents were in the care of DDS and had been placed in several types of facilities to include: nursing homes (N = 3, or, 50%), Specialized home /foster care (N = 1, or 16.5%), an ICF/MR (N = 1, or 16.5%), and a group home (N = 1, or 16.5%).
- Of the six out-of state decedents, five (84%) resided in Maryland and one (16%) resided in Virginia. The race of these decedents included three Blacks and three Whites with their ages ranging from 19 to 86 years.

Location at time of Death

Of the cases reviewed, deaths occurred in locations that included hospitals, nursing homes, residential settings, and hospice. Table 6 presents the number of decedents by year and location of death. In addition to the location of death, the FRC also examined the location of the Ward of the hospital in relation to the Ward of the decedent for calendar years 2004-2006.

Table 6: Location at time of Death

Place of Death	2002 N=2	2003 N=2	2004 N=1	2005 N=10	2006 N=6
Hospital	1	2	1	8	2
Nursing Home	1	0	0	1	2
Hospice	0	0	0	0	1
Residential	0	0	0	1	1

Of the 21 cases reviewed in 2006, 14 (67%) died in a hospital, four (19%) in a nursing home, two (9.5%) in a residential setting, and one (4.5%) in a hospice facility. This finding is relatively consistent with previous FRC Annual Reports. Of the 14 decedents that died in a hospital, 8 (57%) were male and 6 (43%) were female. The average age of these decedents was 56 years.

Cause and Manner of Death

Pursuant to Mayor's Order 2006-123, "Autopsies of Deceased Clients of the Mental Retardation and Developmental Disability Administration",³ the requirement that autopsies be performed on all persons with mental retardation or developmental disability who received services from DDS was eliminated.

Of the 21 cases reviewed in 2006, twenty decedents were autopsied (95%), and one (5%) was examined externally. The one decedent who was examined externally died during calendar year 2005.

Cause of Death

Cause of death is defined as the underlying pathological condition or injury that initiated the chain of events which lead to the death. Consistent with observations in the general population of

³ Mayor's Order 2004-123, Autopsies of Deceased Clients of the Mental Retardation and Developmental Disabilities Administration, September 28, 2006.

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District of Columbia (see OCME Annual Reports 2003 through 2006), diseases of the cardiovascular system predominate as the most prevalent cause of death in the DDS population reviewed. Table 7 lists the proximate causes of death or the underlying pathological condition responsible for the demise in the 21 decedents whose cases were reviewed. The cause of death, as listed below, can bring death about by different mechanisms or terminal events such as arrhythmia, bronchopneumonia, asphyxia, etc.

Table 7: Cause of Death

Cause of Death	Number of Deaths N=21
Cardiovascular Diseases	7
Primary Neurologic Disease	5
Cancer	2
Infectious Diseases	2
Gastrointestinal System Disorders/Conditions	2
Primary Pulmonary Conditions	2
Choking	1

As Table 7 illustrates, Hypertensive Cardiovascular Diseases were the most prevalent in the population reviewed. They were also a contributing factor in three cases. The primary disorders of the Nervous System resulted in five deaths. Seizures were the mechanism of death in three of the deaths and were contributing factors in another three deaths. Ailments of the Respiratory System were responsible for two deaths, one of which was due to complications of Sarcoidosis. In two cases, death was due to infectious diseases, and of these cases, one case was due to Acquired Immune Deficiency Syndrome. There were two cases of cancer (stomach and ovary). Two deaths were caused by disorders of the digestive system, and finally, choking due to aspiration of food material into the airway was the cause of death of one decedent.

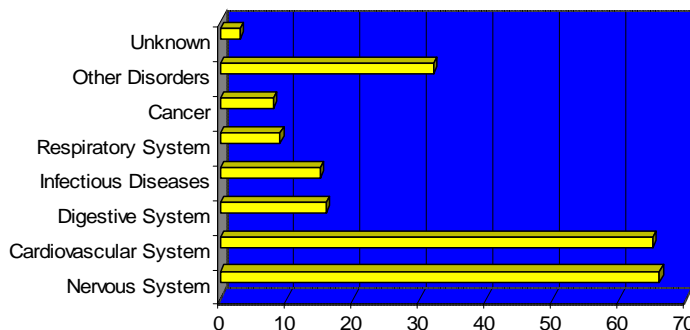
As Figure 7 illustrates, a review of the deceased MRDD population spanning calendar years 2000-2006 revealed that the majority of the decedents succumbed to disorders of the nervous system (N=66 or, 31%). Diseases of the cardiovascular system were the second leading cause with 65 cases (30%). Illnesses of the gastrointestinal system (N=16, or 7%) and infectious diseases (N=15, or 7%) remained the third and fourth leading causes of death respectively in this population.

Disorders of the respiratory system were the fifth leading cause with nine fatalities (4%), followed by eight cases of cancer. Thirty-two cases (15%) were categorized as other disorders to include: blood diseases, choking on food material, diabetes mellitus, morbid obesity, motor vehicle accidents, complications resulting

Figure 7: Leading Causes of Death

Leading Cause of Death 2000-2006

N-214



from therapeutic measures, overdose of a therapeutic drug, unknown injuries, and others. The cause of death for three (1%) decedents remained unknown due to them residing in out-of-state facilities. (See Appendix C: 2006 Causes of Death)

Neuropsychiatric Disorders

Table 8 provides a numerical summary of the first two axes of the Multiaxial Diagnostic System, Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR). Axis I is for reporting Clinical Disorders and Other Conditions That May Be A Focus of Clinical Attention. This includes reporting of Disorders Usually First Diagnosed in Infancy, Childhood or Adolescence excluding Mental Retardation. Axis II is for reporting Mental Retardation and Personality Disorders.

Mental Retardation has been distinguished by level of severity, cognitive functioning and adaptive functioning. When significant neurologic dysfunction is associated with other organ system anomalies, an individual's life expectancy may be shortened.

Table 8: Neuropsychiatric Disorders by Axis

AXIS I		AXIS II		
Disorders	(N = 10)	Mental Retardation Level of Severity	Cognitive (N = 21)	Adaptive (N = 4)⁴
Intermittent Explosive Disorder	1	Profound	6	1
Depressive Disorder	3	Severe	7	2
Dementia	1	Moderate	5	
Psychotic Disorder NOS	2	Mild	3	1
Schizoaffective Disorder	1			
Obsessive Compulsive Disorder	2			

As Table 8 depicts, of the 21 cases reviewed during 2006, 10 decedents had received Axis I diagnoses. The six Axis I diagnostic disorders are as follows: Intermittent Explosive Disorder, Depressive Disorder, Dementia Psychotic Disorder NOS, Schizoaffective Disorder, and Obsessive Compulsive Disorder.

Of the 21 cases reviewed during 2006, only four decedents received adaptive scores. The degrees of severity reflect the level of intellectual (cognitive) impairment. Of the deaths reviewed (N=21), six (29%) were diagnosed with Profound Mental Retardation, seven (33%) were Severe, five (24%) were Moderate, and three (14%) were Mild.

Manner of Death

Manner of death refers to the circumstantial events surrounding the death. The manner of death, as determined by the forensic pathologist, is an opinion based on the known facts concerning the circumstances leading up to and surrounding the death, in conjunction with the findings at autopsy and laboratory tests. Unlike the cause of death, manner can differ depending on the conditions and contributing factors revealed during the investigation and/or autopsy.

⁴ Adaptive functioning is a crucial component of the diagnosis for mental retardation. However, only four cases reviewed reported current levels of adaptive functioning.

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Table 9: Manner of Death by Year

Manner of Death	N=21					Percentage
	2002 N=2	2003 N=2	2004 N=1	2005 N=10	2006 N=6	
Natural	2	2	1	9	6	95%
Accident	0	0	0	1	0	5%

As shown in Table 9, the majority (N=20, or 95%) of the deaths reviewed was determined to be Natural; one (5%) was Accidental. There were no fatalities attributed to Suicide, Homicide or Undetermined manners of death.

“AN EDUCATIONAL OVERVIEW: CEREBRAL PALSY”

Cerebral palsy is an umbrella term encompassing a group of non-progressive, non-contagious neurological disorders that cause physical disability in human development, specifically movement and posture. The incidence in developed countries is approximately 2-2.5 per 1000 live births, and incidence has not declined over the last 60 years despite medical advances. Cerebral palsy can occur during pregnancy (about 75 percent), during childbirth (about 5 percent) or after birth (about 15 percent). In 80 percent of the cases, the cause is unknown; however for the small number where known, the cause includes infection, malnutrition, and/or significant head trauma in very early childhood. Cerebral palsy usually takes several months to several years to diagnose.

CEREBRAL PALSY WITHIN THE DISTRICT OF COLUMBIA DECEDENT POPULATION FOR CALENDAR YEARS 2004-2006

A statistical review of cases in the District's DDS decedent population for calendar years 2004 through 2006 shows that of the 99 decedents, 21 (21%) were diagnosed with cerebral palsy.

Table 10: CP within the DC Decedent Population (2004-2006) N=21

2004 N=36	Male	Female
N=8 (22%)	4	4
2005 N=34	Male	Female
N=7 (20%)	5	2
2006 N=30	Male	Female
N=6 (20%)	3	3

Results presented in Table 10 indicate a range between 20 to 22 percent of the decedent population (N=21) was diagnosed with cerebral palsy during calendar years 2004 through 2006 and ranged in age from 19 to 76 years. Of these decedents, 16 (72%) were Black, four (19%) were White, and one (5%) was Hispanic. Fifty-seven percent were male (N=12) with an average age of 45.6 years, and 43% (N=9) were female with an average age of 47.8 years.

Since cerebral palsy refers to a group of disorders, there is no single known cause. Some major causes are asphyxia, hypoxia of the brain, birth trauma or premature birth, genetic susceptibility, certain infections in the mother during and before birth, central nervous system infections, and trauma. The condition may be caused by toxins, physical brain injury, incidents involving hypoxia to the brain (such as near drowning), and encephalitis or meningitis. However the cause of most individual cases of cerebral palsy is unknown.

Cerebral palsy (CP) is divided into four major classifications to describe the different movement impairments. These classifications reflect the area of brain that has been damaged. The four major classifications are:

- Spastic: By far the most common type of CP, occurring in about 70% of all cases. Persons with this type are hypertonic and have an essentially neuromuscular condition stemming from damage to the corticospinal tract, motor cortex, or pyramidal tract that affects the nervous system's ability to receive gamma amino butyric acid in the area(s) affected by the spasticity.
- Athetoid: Also called dyskinetic, mixed muscle tone, or hypertonia. Individuals with athetoid CP have trouble holding themselves in an upright, steady position for sitting or walking, and often show involuntary motions. Because of their mixed tone and trouble keeping a position, they may not be able to hold onto things (like a toothbrush or fork or pencil). About one-fourth of all people with CP have the athetoid type.
- Ataxic: Damage to the cerebellum which results in problems with balance, especially while walking. It is the most unusual (rare) type, occurring in at most 10% of all cases. Some of these individuals have hypertonia and tremors. Motor skills like writing, typing, or using scissors might be difficult and it is common for these individuals to have difficulty with visual or auditory processing of objects and instability in balance and relation to gravity.
- Mixed: In 30 percent of all CP cases, the spastic form is found along with one of the other types. CP's resultant motor disorder(s) are sometimes, though not always, accompanied by "disturbances of sensation, cognition, communication, perception, and/or behavior, and/or by a seizure disorder"

Although CP is a non-progressive disorder, meaning the actual brain damage does not worsen, the symptoms can become worse over time due to 'wear and tear' and secondary deformities, such as hip dislocation and scoliosis of the spine, are common. Each type of CP is characterized by abnormal muscle tone, posture, reflexes, or motor development and coordination. The classical symptoms are spasticity, unsteady gait, and dysarthria, and soft tissue findings consisting largely of decreased muscle mass, but taken on the whole, CP symptomatology is as diverse as the individuals who have it. People who suffer from CP tend to develop arthritis at a younger age due to secondary symptoms such as seizures, spasms, and other involuntary movements, speech or communication disorders, hearing or vision impairments, cognitive disabilities, learning disabilities, and/or behavioral disorders.

There is mental retardation in 60% of the cases of CP, due to brain damage, and survival has been shown to be associated with the ability to ambulate, roll, and self-feed. Treatment and therapy may include physical, occupational, and speech therapy; drugs to control seizures, alleviate pain, relaxing muscle spasms, and contracting muscles; surgery to correct anatomical abnormalities or release tight muscles; braces and other orthotic devices; wheelchairs and rolling walkers; and communication aids such as computers with attached voice synthesizers. Overall, cerebral palsy ranks among the most costly congenital conditions in the world to manage effectively.⁵

⁵ "Cerebral Palsy." (National Center on Birth Defects and Developmental Disabilities, October 3, 2002), www.cdc.gov

Level of Disability and Risk Factors

Although mental retardation is not necessarily associated with an increased premature death rate, certain key disabilities can be used to accurately predict life expectancy in individuals with cerebral palsy and mental retardation. These disabilities include: (1) the presence and severity of mental retardation, (2) inability to speak intelligible words, (3) inability to recognize voices, (4) inability to interact with peers, (5) severity of physical disability, (6) use of tube feeding, (7) incontinence, and (8) presence and severity of seizures.⁶ In most cases, persons with cerebral palsy have a normal life expectancy; however, survival has been linked with several domains such as mobility and feeding limitations, and severity of cognitive abilities. Individuals with severe to profound cognitive impairment, in addition to age, race and gender, experience a decreased life expectancy. Neurologic dysfunction resulting in immobility, significant oral motor dyscoordination, dysphasia, and aspiration confers a greater risk of premature death than mental retardation itself. When significant neurologic dysfunction is associated with other organ system anomalies, an individual's life expectancy may be shortened further.

Persons with severe and profound levels of cognitive and adaptive disability typically have additional co-morbid conditions (other medical diagnoses). For example, one in five individuals with mental retardation may also have cerebral palsy, epilepsy, or other debilitating conditions. However, two critical co-morbid risk factors include mobility limitations and eating impairments.⁷ These two risk factors tend to have a significant effect on overall morbidity and mortality. Thus, mobility impairments and the need for special assistance when eating are two risk factors that placed individuals at a higher mortality risk. Of the twenty-one 2004-2006 decedents diagnosed with cerebral palsy:

- Sixteen, or 76% were diagnosed as profound
- Four, or 19% were diagnosed as severe
- One, or 5% was diagnosed as mild
- Seventeen, or 81% had a feeding impairment
- Twenty, or 95% had mobility limitations

The fatality review process also continued to review these two factors, feeding impairments and mobility limitation, for the total number of decedents during calendar years 2004 through 2006. As illustrated in Table 11, of the 99 decedents, 43, or 43% were classified as profoundly retarded, 22, or 22% were classified as severely retarded, 21, or 21% were classified as moderately retarded, and 13 or, 13% were classified as mildly retarded.

Table 16 provides information on the decedents by level of disability for calendar years 2004 through 2005, as well as the identified risk factors of feeding and mobility impairments.

Table 11: Level of Disability and Risk Factors for calendar years 2004-2006

⁶ Life expectancy for children with cerebral palsy and mental retardation: Implications for life care planning; Richard T. Katz; Neurorehabilitation, Issue: Volume 18, number3/2003, pages 251-270.

⁷ American Dietetic Association, Providing nutritional services for infants, children and adults with developmental disabilities and special health care needs, May 2003.

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Total N=100	Level of Disability	Percentage of Population	No Risk Factors Identified	Mobility Limitations	Feeding Impairments	Both Risk Factors
Mild	13	13%	7	3	3	1
Moderate	20	20%	8	10	2	0
Severe	22	22%	8	13	4	3
Profound	45	45%	9	34	20	18

- Of the 45 decedents classified as profoundly retarded, 34 (75%) had mobility limitations; 20 (45%) had feeding impairments; 18 (41%) of the decedents experienced both risk factors; and nine (20%) of the decedents had none of the identified risk factors.
- Of the 22 decedents classified as severely retarded, 13 (59%) had mobility limitations; four (18%) had a feeding impairment; three (14%) of these decedents experienced both risk factors; and eight (36%) of the decedents had none of the identified risk factors.
- Of the 20 decedents classified as moderately retarded, 10 (50%) had mobility limitations; two (10%) had a feeding impairment; none of this group had both risk factors; and eight (40%) had none of the identified risk factors.
- Of the 13 decedents classified as mildly retarded, three (23%) of the decedents had mobility limitations⁸; three (23%) had a feeding impairments; one (7%) had both risk factors present; and seven (54%) had none of the identified risk factors

As highlighted in Table 11, in line with expected trends, the relationship between level of mental retardation and mortality shows that persons with the most significant disabilities and health care needs (severe and profound, N=66 (67%) had a higher rate of mortality during 2004 through 2006 calendar years. Overall, 68% of the decedents (N=67) had at least one of the identified risk factors associated with increased mortality.

⁸ Mobility limitations include the use of adaptive equipment, and/or wheelchair-dependent.

APPENDICES

Fatality Review Committee Handbook
Mayor's Order

Mental Retardation Developmental Disabilities Review Committee

GOVERNMENT OF THE DISTRICT OF COLUMBIA

ADMINISTRATIVE ISSUANCE SYSTEM

Mayor's Order 2005-143
September 30, 2005

SUBJECT: Re-establishment - District of Columbia Mental Retardation and
Developmental Disabilities Fatality Review Committee

ORIGINATING AGENCY: Office of the Mayor

By virtue of the authority vested in me as Mayor of the District of Columbia by section 422(2) of the District of Columbia Home Rule Act (Home Rule Act), approved December 24, 1973, 87 Stat. 790, D.C. Official Code § 1-204.22 (2) and (11)(2001), it is hereby **ORDERED** that:

I. RE-ESTABLISHMENT

There is hereby re-established in the Executive branch of the government of the District of Columbia the District of Columbia Mental Retardation and Development Disabilities ("MRDD") Fatality Review Committee (hereinafter referred to as the "Committee").

II. PURPOSE

The Committee shall examine events and circumstances surrounding the deaths of District wards over the age of 18 years with mental retardation or a developmental disability in order to: gather and analyze empirical evidence about fatalities in this population; safeguard and improve the health, safety and welfare of District wards over the age of 18 years with mental retardation or a developmental disability; reduce the number of preventable deaths; and promote improvement and integration of both the public and private systems serving District wards over the age of 18 years with mental retardation or a developmental disability. For purposes of this Mayor's Order, a District ward over the age of 18 years with mental retardation or a developmental disability may be defined as an individual committed by a court to the care and custody of the District government, or who is under the supervision or care of the District government or of programs contracted by the District government to deliver such care, for reasons of mental retardation or developmental disability.

III. DUTIES

The duties of the Committee shall include:

- a. Expediently reviewing deaths of District wards over the age of 18 years with mental retardation or a developmental disability, especially those who reside in group homes, foster homes, nursing homes or any other residential or health care facilities licensed or contracted by the District;
- b. Identifying the causes and circumstances contributing to deaths of District wards with mental retardation or a developmental disability;
- c. Reviewing and evaluating services provided by public and private systems that are responsible for protecting or providing services to District wards over the age of 18 years with mental retardation or a developmental disability, and assessing whether said entities have properly carried out their respective duties and responsibilities; and
- d. Based on the results of the reviews (both individual and in the aggregate), identifying strengths and weaknesses in the governmental and private agencies and/or programs that serve District wards over the age of 18 years with mental retardation or a developmental disability and making recommendations to the Mayor and the agencies and programs directly to implement systemic changes to improve services or to rectify deficiencies. The recommendations may address, but are not limited to, proposing statutes, policies or procedures (both new or amendments to existing ones); modifying training for persons who provide services to District wards over the age of 18 years with mental retardation or a developmental disability; enhancing coordination and communication among entities providing or monitoring services for District wards over the age of 18 years with mental retardation or a developmental disability; and facilitating investigations of fatalities.

IV. FUNCTIONS

The functions of the Committee shall include:

- a. Developing and issuing procedures governing its operations within ninety (90) days of the effective date of this Mayor's Order. The procedures shall include, at a minimum, the following:
 1. Methods by which deaths of District wards over the age of 18 years with mental retardation or a developmental disability are identified and reported to ensure expeditious reviews;

2. A process by which fatality cases are screened and selected for review;
 3. A method for ensuring that all information identifying District wards over the age of 18 years with mental retardation or a developmental disability, their families and others associated with the cases or the circumstances surrounding the deaths, including witnesses and complainants, is protected against undue disclosure. This is to ensure that steps are taken to protect the right to privacy of an individual and his or her family in conducting investigations, disseminating information to Committee members, reporting as required by the Mayor's Order, and maintaining case records for the Committee;
 4. A method for gathering individual and cumulative data from the reviews;
 5. A method for reviewing whether recommendations generated by the Committee are being implemented and identifying problems related to obstacles/barriers to implementation; and
 6. A method for evaluating the work of the Committee that takes into account community responses to the deaths of District wards with mental retardation or a developmental disability.
- b. On or about December 31st of each year, producing an annual report that provides information obtained from the reviews of deaths that occurred during the previous calendar year. The annual report shall be submitted to the Mayor and made available to the public. The information to be contained in the report shall include at a minimum:
1. Statistical data on all fatalities of District wards with mental retardation or a developmental disability reviewed by the Committee, including numbers reviewed, demographic characteristics of the subjects, and causes and manners of deaths;
 2. Analyses of the data generated by the reviews, to demonstrate the types of cases reviewed (which may include illustrative case vignettes without identifying information), similarities or patterns of factors causing or contributing to the deaths, and trends (including temporal and geographic); and
 3. Recommendations generated from the reviews, including service enhancements, systemic improvements or reforms, and changes in laws,

policies, procedures or practices that would better protect District wards with mental retardation or a developmental disability and that could prevent future deaths.

V.

COMPOSITION

- a. Members shall be appointed by the Mayor based on individual expertise in relevant disciplines and their familiarity with the laws, standards, and services related to the protection of the health and welfare of District wards over the age of 18 years with mental retardation or a developmental disability. As such, the composition of the Committee shall reflect medical and clinical professionals from various disciplines who serve consumers with mental retardation or developmental disabilities. An effort shall be made to ensure representation from each geographical ward of the District.
- b. The Committee membership shall consist of:
 1. Five (5) members representing the following District government agencies:
 - A. Metropolitan Police Department, Special Victims Unit;
 - B. Office of the Chief Medical Examiner (OCME);
 - C. Office of the Inspector General (OIG), Medicaid Fraud Unit;
 - D. Department of Human Services (DHS), Mental Retardation and Developmental Disabilities Administration (MRDDA); and
 - E. Fire and Emergency Medical Service Department (FEMSD).
 2. A minimum of six (6) and no more than eight (8) public members from the community who shall not be employees of the District government, up to three (3) of whom shall be clinicians with experience in the evaluation and treatment of persons with mental retardation and developmental disabilities. The public members shall include at least:
 - A. Two (2) faculty members from schools of social work at colleges or universities located in the District;

- B. Two (2) physicians who practice in the District with experience in the evaluation and treatment of persons with mental retardation or developmental disabilities;
- C. One (1) psychiatrist and one (1) psychologist or other mental health professional who is licensed to practice in the District with experience in the evaluation and treatment of persons with mental retardation or developmental disabilities.

VI. TERMS

- a. Public members appointed to the Committee shall serve for three (3) year terms, except that of the members first appointed, one-half shall be appointed for three (3) year terms and one-half for two (2) year terms. The date on which the first members are installed shall become the anniversary date for all subsequent appointments.
- b. Members appointed to represent District government agencies shall serve only while employed in their official positions and shall serve at the pleasure of the Mayor.
- c. A public member shall not serve more than two (2) consecutive full terms.
- d. A member appointed to fill an unexpired term shall serve for the remainder of that term.
- e. A member may hold over after the member's term expires until reappointed or replaced.
- f. A public member may be excused from a meeting for an emergency reason. A public member who fails to attend three (3) consecutive meetings shall be deemed to be removed from the Committee, and a vacancy created. Such vacancies shall be filled by the Mayor as outlined in section V of this Mayor's Order.
- g. A public member may be removed by the Mayor for personal misconduct, neglect of duty, conflict of interest violations, incompetence, or official misconduct. Prior to removal, the public member shall be given a copy of any charges and an opportunity to respond within 10 business days following receipt of the charges. Upon a review of the charges and the response, the Director of the Office of Boards and Commissions, Executive Office of the Mayor, shall refer the matter to

the Mayor with a recommendation for a final decision or disposition. A public member shall be suspended by the Director of the Office of Boards and Commissions, Executive Office of the Mayor, on behalf of the Mayor, from participating in official matters of the Committee pending the consideration of the charges.

VII. ORGANIZATION

- a. The Mayor shall appoint the Chief Medical Examiner and the Administrator, Mental Retardation and Developmental Disabilities Administration, Department of Human Services, as Co-Chairpersons of the Committee, and they shall serve in these capacities at the pleasure of the Mayor.
- b. The Committee may establish its own bylaws and rules of procedure.

VIII. COMMITTEE COORDINATOR: ROLES AND RESPONSIBILITIES

The Chief Medical Examiner shall appoint a Committee Coordinator who shall serve as the focal point for receiving case notifications and information, as well as for the appropriate dissemination of information to the Committee.

IX. FULL COMMITTEE

- a. A majority of the members shall be present to constitute a quorum.
- b. Meetings of the full Committee shall be held for the purposes of:
 1. Conducting case reviews or assessing additional data from prior cases that have since become available;
 2. Considering recommendations arising from available case reviews;
 3. Preparing an annual report; and
 4. Conducting any other business necessary for the Committee to operate or fulfill its duties.

- c. Case review meetings of the full Committee shall be held monthly, if there are cases for review. After procedures have been established and tested, the Committee may consider holding case review meetings every other month (bi-monthly), if practicable. The full Committee may also convene additional meetings as needed for additional case reviews, or for other specific purposes of the Committee, including the development of recommendations or preparation of the annual report.
- d. The Committee shall conduct multi-disciplinary reviews of the events and circumstances surrounding the deaths of District wards over the age of 18 years with mental retardation or a developmental disability as defined in section II, above, in order to provide the data to fulfill the purposes and duties of the Committee as enumerated in sections II and III, respectively.
- e. Case reviews will occur at the first Committee meeting after the Committee receives notification of the fatality, or at the first meeting after sufficient materials are received for conducting the review. The review may be preliminary, pending conclusion of the investigation and prosecution, or release by the prosecutor to conduct the review, at which time a comprehensive review shall be conducted.
- f. The case review process shall include presentation of the case summary, followed by presentations of relevant information concerning the death by any agencies or persons involved with District wards over the age of 18 years with mental retardation or a developmental disability or investigating the event.
- g. Following presentation of the facts, the Committee will discuss the case and any issues that it raises, guided by the following principles and questions:
 - 1. What factors or circumstances caused or contributed to the death? (This may include consideration of social service delivery and coordination to District wards over the age of 18 years with mental retardation or a developmental disability and their families and compliance with, or development of, applicable or needed laws, procedures and regulations.)
 - 2. What responses and investigations resulted from the death? (This includes whether all necessary agencies were notified and responded, and whether any corrective actions were instituted.)

3. Were the services, interventions and investigations concerning the District ward over the age of 18 years with mental retardation or a developmental disability appropriate and adequate for his/her needs? (In other words, did the systems and agencies provide and plan effectively for the District ward over the age of 18 years with mental retardation or a developmental disability?)
 4. Were the staff involved with the District wards over the age of 18 years with mental retardation or a developmental disability adequately prepared, trained, and supported to perform their duties correctly?
 5. Was there adequate communication and coordination among the various entities involved with the District ward over the age of 18 years with mental retardation or a developmental disability?
 6. Are the applicable statutes, regulations, policies and procedures adequate to serve the needs of the target population? If not, what changes to them are needed?
- h. Based on the case discussion, the Committee shall formulate applicable recommendations as enumerated above in section III (d) and section IV (a) and (b)(3), for further consideration and possible inclusion in the annual report.

X.

SUBPOENA POWER

- a. When necessary for the discharge of its duties, the Committee shall have the authority to issue subpoenas to compel witnesses to appear and testify and to produce books, papers, correspondence, memoranda, documents, or other relevant records. The Mayor hereby delegates the said authority to the Committee, to the extent necessary and appropriate to effectuate the Committee's duties, pursuant to D.C. Official Code §1-301.21(a)(2001).
- b. Except as provided in paragraph (3) of this section, subpoenas shall be served personally upon the witness or his or her designated agent, not less than five (5) business days before the date the witness must appear or the documents must be produced, by one of the following methods, which may be attempted concurrently or successively:

1. By a special process server, at least 18 years of age, designated by the Committee from among the staff of the Committee or any office or organization designated by the Committee; provided, that the special process server is not directly involved in the investigation; or
2. If, after a reasonable attempt, personal service on a witness or witness' agent cannot be obtained, a special process server identified in paragraph (1) may serve a subpoena by registered or certified mail not less than eight (8) business days before the date the witness must appear or the documents must be produced.
3. If a witness who has been personally summoned neglects or refuses to obey the subpoena issued pursuant to this section, the Committee may apply to the Superior Court of the District of Columbia for an order compelling the witness so summoned to obey the subpoena.

XI.

CASE REVIEW CRITERIA AND PROCEDURES

- a. All deaths of District wards over the age of 18 years with mental retardation or a developmental disability shall be reviewed by the Committee.
- b. Factors of particular concern for review include:
 1. All violent or unexplained manners of death (i.e., homicide, suicide, accident or undetermined), which include all deaths caused by injuries, including:
 - A. Fractures;
 - B. Blunt trauma, including fractures;
 - C. Burns;
 - D. Asphyxia or drowning;
 - E. Poisoning or intoxication;
 - F. Gunshot wounds; or
 - G. Stabbing or cutting wounds;

2. Abuse, either physical or sexual;
 3. Neglect, including medical and custodial;
 4. Malnourishment or dehydration; and
 5. Circumstances or events deemed suspicious.
- c. The Committee may, at its discretion, review groups of sudden, unexpected or unexplained deaths of District wards with mental retardation or a developmental disability without regard to age, in order to examine aggregate data in order to address specific issues or trends.
- d. The deaths of District wards over the age of 18 years with mental Retardation or a developmental disability who live in facilities outside the District, or who die outside the District, will be subject to review by the Committee, and will be included in the annual report, both for statistical analysis and recommendations. The Co-ordinator shall serve as liaison to his or her counterparts in foreign jurisdictions for the purpose of gathering information and obtaining documents (e.g., police or autopsy reports) to complete the review.

XII.

CASE NOTIFICATION PROCEDURES

- a. District agencies and service providers contracted by the District to serve District wards over the age of 18 years with mental retardation or a developmental disability shall provide written notification to the Committee within 24 hours of any death of a District ward over the age of 18 years with mental retardation or a developmental disability, or within 24 hours of becoming aware of such a death. The sources of case notifications will include but are not limited to the:
1. Mental Retardation and Developmental Disabilities Administration (MRDDA), Department of Human Services (DHS);
 2. Contracted service providers (e.g., group home staff);
 3. Office of Inspections and Compliance (OIC), DHS;
 4. Office of the Chief Medical Examiner (OCME);

5. Metropolitan Police Department (MPD);
 6. Office of the Inspector General (OIG);
 7. Office of the Attorney General (OAG);
 8. Department of Health (DOH); and
 9. Department of Mental Health (DMH).
- b. Case notification reports should include for the affected District ward over the age of 18 years with mental retardation or a developmental disability:
1. Demographic data (name, age/date of birth, race, gender);
 2. Address;
 3. Parents/guardians;
 4. Circumstances of the death (date, time, location, activities, risk factors, witnesses or sources of information);
 5. Agencies investigating the death; and
 6. History of the involvement of government agencies or contacted service providers.
- c. MPD, DHS (OIC and MRDDA), DOH and OIG shall provide the Committee copies of all death reports resulting from any investigations that are conducted concerning District wards over the age of 18 years with mental retardation or a developmental disability. The OCME shall provide the Committee copies of all autopsy reports resulting from autopsies and death investigations conducted on District wards over the age of 18 years with mental retardation or a developmental disability. These reports shall be provided within five (5) days after they are completed.

XIII.

NOTIFICATION OF PARTICIPANTS

- a. Notification shall be provided in writing to all review participants two (2) weeks prior to the review. Notification shall include sufficient information for the case to be researched, the record identified and reviewed and adequate information related to the nature of the agency's involvement collected

for presentation during the review meeting. Any agreed information shall be provided to the Committee Coordinator prior to the review.

- b. Similar written notification shall be provided to all independent and/or community individuals invited to the review meeting. These may include experts from various relevant disciplines or service areas.

XIV.

RECORDS

All records and reports shall be maintained in a secured area with locked file cabinets. Three (3) years after the annual report has been distributed, all supporting documentation in each fatality record shall be destroyed. The only material that will be maintained in a fatality record will be the following:

1. Initial Data Form;
2. Final Report; and
3. Death Certificate.

XV.

CONFIDENTIALITY

- a. A key tenet of the Committee is the necessity for keeping confidential all information obtained by, presented to and considered by the Committee, consistent with the confidentiality provisions of D.C. Official Code § 7-1305.12 (2001).
- b. Any information gathered in preparation for or divulged during committee reviews shall not be disclosed except as provided in subsection (d) of this section and applicable law, including the Freedom of Information Act, D.C. Official Code § 2-531 *et seq.* (2001).
- c. All participants in the Committee proceedings shall be required to sign a confidentiality statement during all Committee case review meetings and in general meetings where any specific case is discussed. Case-specific information distributed during the meeting shall be collected at the end of each review. Any participant who is not willing to sign a confidentiality statement or to abide by the confidentiality requirements shall not be allowed to participate in case review meetings.

- d. Methods for ensuring that all information identifying third persons such as witnesses, complainants, agency, institution, or program staff or professionals involved with the family are protected against disclosure are:
 - 1. The same procedures established for District wards over the age of 18 years with mental retardation or a developmental disability and their families above shall be followed for these entities.
 - 2. Access to primary documents will be limited to the staff of the Committee and the chair of the review meeting.
 - 3. Initials only will identify third persons in materials for distribution.

XVI. RECOMMENDATIONS

- a. Draft recommendations shall be developed by the Committee Coordinator based on issues raised during the reviews.
- b. Draft recommendations shall be distributed to agencies and members for review and comment. Recommendations shall be finalized based on the comments received, including discussion at meetings of the full Committee.
- c. Final recommendations shall be incorporated into the annual report and forwarded to the Mayor. Interim recommendations may be forwarded to the affected entities for expeditious implementation, at the approval of the Committee.
- d. Representatives of agencies, institutions and programs may be invited to full Committee meetings to present their plans for, or progress made towards, implementing the recommendations.

XVII. COMPENSATION

Members of the Committee shall serve without compensation, except that a public member may be reimbursed for expenses incurred in the authorized execution of official Committee functions, if approved in advance by the Chief Medical Examiner or designee, and subject to the appropriation of and the availability of funds.

XVIII. ADMINISTRATION

The Office of the Chief Medical Examiner shall provide administrative support for the Committee, including the services of the Coordinator.

XIX. LEGAL APPLICATION

Nothing in this Mayor's Order shall be deemed to create legal rights or entitlements on the part of District wards over the age of 18 years with mental retardation or a developmental disability, their families, or estates, or to give rise to causes of action prosecutable by said persons.


XX. RECISSIONS

Mayor's Order 2000-82, dated May 30, 2000, and Mayor's Order 2001-27, dated February 14, 2001, are superseded and rescinded in their entirety.

XXI. EFFECTIVE DATE: This Order shall become effective immediately.


ANTHONY A. WILLIAMS
MAYOR

ATTEST:


SHERRYL HOBBS NEWMAN
SECRETARY OF THE DISTRICT OF COLUMBIA

2006 MRDD FATALITY REVIEW RECOMMENDATIONS

During calendar year 2006, based on the review of 21 cases, the MRDD FRC made 26 new recommendations, and re-issued several recommendations from previous years. These recommendations focused on issues of guardianship, end-of-life preparedness, training, and health care. The FRC also made recommendations to improve timeliness for obtaining information and data required for reviews, and improve the District's overall review process, and collaborative methods of operating. Further, the FRC began to conduct a more thorough evaluation of the review process and operational modalities currently in place. It is the FRC membership's hope that this evaluation will assist in identifying systemic issues and concerns that are obstructive to the process, and assist in devising ways to streamline information to allow the FRC to operate more efficiently. The FRC recommendations issued in 2006 are as follows:

FRC Recommendation	Status
DDS should review care provided by hospitals and group homes, and provide a report of the findings to the FRC committee within ten (10) business days.	DDS responded timely with a written response to the investigative request.
DDS should ensure all individuals, especially those with medical conditions that will likely warrant ongoing diagnostic testing and medical treatment, have legally be appointed guardians who can assist in decision-making and prevent treatment delays.	Lengthy Response Received and on File
DDS should review this provider's current organizational structure to determine whether RN assignment provides a sufficient number of registered nurses to ensure there is adequate health care oversight and LPN supervision.	DDS has completed the review of the provider's organizational structure to determine whether there was sufficient RN supervision of the LPN.
DDS should hire an independent contractor to review a sample of ISP's to ensure the quality of the documentation and care.	DDS will take the "Person Centered Agenda" forward in partnership with key stakeholders, public and private, that are interested in developing a more responsive and individualized person-centered plan.
DDS should proactively review end-of-life planning in the ISP for all consumers, along with guardianship/decision-maker at least on an annual basis.	DDS has revised the Individual Support Plan (ISP) to incorporate the decision-making process that allows guardians to support individuals in making appropriate decisions for the care of the individuals that lack the capacity to make decisions for themselves.
DDS should consider mandatory training on end-of-life issues for all staff	DDS provide a comprehensive curriculum of resources, and materials aimed at enhancing the skills of staff involved in end-of-life and critical care issues. The training includes didactic presentations on pain related issues (see attachment 1:Pain Management Presentation), and guardianship for health care decisions
DDS should develop an agreement with their providers to legally	In lieu of developing an agreement with providers, a formalized agreement will be

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transport their deceased consumers across state line(s) to OCME for autopsy.	developed with a transportation service firm that is legally authorized to transport deceased bodies. In the interim, DDS's Transportation Director will continue coordinating with a local funeral home to transport deceased consumers across state line to OCME for autopsy.
DDS should provide a clinical summary of the medical record with an updated history to the Office of the Chief Medical Examiner before the cause and manner of death is completed.	DDS's Medical Officer has prepared a clinical summary as requested.
DDS systemically review the care of all of its consumers and all consumers over the age of 50 have an end-of-life plan and guardianship (as necessary) incorporated in the ISP and updated yearly. Sample plans should be provided with the response.	A comprehensive work plan has been developed to ensure that all DDS consumers have end-of-life plans and guardianship incorporated in the ISP and updated yearly.
DDS contract provider administrator be trained in the mandatory areas with documentation forwarded to the FRC.	The DDS Training Department provides on-going training in the eight mandatory areas, i.e., Incident Management, ISP Policy, and Psychotropic Drug Reviews.
DDS should provide copies of the current ISP for all 199 high-risk consumers with validated end-of-life plans and guardianship documentation within 30 days of the request.	Of the pool of 194 at-risk consumers, 15 have guardians appointed and 15 have petitioned guardianship within 30 days and awaiting a decision. By June 30, 2006, DDS's Case Management Division (CMD) will establish a policy and process for end-of life planning and decision making, which will be incorporated into the consumer's ISP. The DDS process shall incorporate end-of-life planning during the initial development of the ISP and annually at the ISP meetings.
DDS should forward documentation of all DDS training curriculums, instructors, and attendance for LPN's to the committee for review.	Lengthy Response Received and on File
DDS should review each group home/ICF-MR to ensure adequate care is being provided.	Lengthy Response Received and on File
DDS should request "best practice" data from the Columbus Investigative Group (CIG) regarding prescribing multiple medications for fragile consumers as suggested in the investigative reports.	DDS will research best practice in this area as part of a 2008 initiative. DDS is not permitted to sole source this request to the Columbus Investigative Group, but is identifying key health initiatives to address immediate and critical health care needs, and will prepare statements of work as needed for outside assistance in these areas.
DDS should seek the development of a legislative proposal to address guardianship and end-of-life issues.	Lengthy Response Received and on File
DDS should establish formal educational, training and licensing requirements for all case managers.	DDS has established mandatory training for case management and is developing expanded professional and skill development programs in FFY 2008. DDS is not currently considering changes to education and licensure requirements in the DDA case management position description.
DDS should develop a consumer advocacy program (using the Department of Mental Health's Model) to monitor group homes and other care provided; and to recommend members to participate on this committee.	A member of Project Action (consumer advocacy group) sits on the FRC. DDS is developing an Office of Rights and Advocacy and will develop a strategic plan for consumer involvement in all aspects of DDS in the third quarter of FFY 2008.
DDS should invite the Directors of group homes to attend the	DDS invites the Provider agency representative to the DDA internal Mortality

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MRDD FRC.	Review meetings. DDS will invite agency representatives as requested to FRC meetings beginning January 2008.
DDS should contact the Epilepsy Foundation regarding smoking cessation guidelines and educational material for consumers with seizures.	DDS will direct the Health and Wellness Unit Manager to do so in January 2008.
DDS should incorporate an on-going training program for all clinical and direct-care staff, to include documentation, nutritional and pain management curriculums.	Lengthy Response Received and on File
DDS should conduct training on the proper transfer of records and consumer information via the medical passport when consumers are transferred between hospitals and other long-term care facilities.	This information is thoroughly covered in the DDS mandated Medical/Dental policy training for all staff working with people with disabilities.
DDS should seek measures to maintain consumers in one hospital/facility (regardless of the number of emergency admissions, as appropriate) to maintain continuity of care.	Pending Response: Recommendations required amendment
DDS should establish policies and practices that require staff to contact the primary care physician for emergency admissions to allow direct admission to a hospital to prevent and/or reduce emergency room visits.	DDS commits to support this practice beginning immediately through case management, clinical standards, and training.
DDS should instruct all providers and staff to contact 911 (EMS) immediately upon signs of respiratory distress.	DDS guidance to providers clearly requires agency staff to contact 911 in the event of respiratory distress. DDS through the Training Dept., Case Management, and Quality Enhancement will reiterate this requirement through training, case management, and technical assistance activities.
DDS should include the requirement of a complete medical passport (with periodic updated data) for each consumer is included in the Provider's contractual agreement with the District.	DDS is implementing a Basic Assurance Standards Authorization process.
DDS should continue its efforts to ensure those consumers in need of a guardian are accommodated.	Efforts to gain guardianship and/or alternative decision makers for people who need them are an ongoing priority and part of the delivery system.

2006 CAUSES OF DEATH
DISTRICT OF COLUMBIA DEATH CERTIFICATE REVIEW

2002 Deaths Reviewed:

1. Metastatic Ovarian Carcinoma
2. Down Syndrome with Seizure Disorder and Pulmonary Complications

2003 Deaths Reviewed:

1. Complications of Cerebral Palsy
2. Metastatic Gastric Cancer

2004 Deaths Reviewed:

1. Complication following Cholecystectomy, Herniorrhaphy and Partial Gastectomy for the treatment of Cholecystitis, Ventral Hernia Following Nephrectomy of Unknown etiology and perforated gastric ulcer due to Peptic Ulcer Disease

2005 Deaths Reviewed:

1. Bacterial Endocarditis of Mitral Valve
2. Asphyxia Due to aspiration of food material in airway
3. *The autopsy findings are consistent with the cause of death as stated on the death certificate: Respiratory Failure
4. Complications of Hypertension and Arteriosclerotic Cardiovascular Disease
5. Seizure Disorder of unknown etiology
6. Arteriosclerotic and Hypertensive Cardiovascular Disease with Myocardial Fibrosis
7. Hypertensive Cardiovascular Disease
8. Coronary Arteriosclerotic Cardiovascular Disease
9. Gastrointestinal Hemorrhage due to esophageal varices due to cirrhosis of the liver due to Hepatitis B
10. Pulmonary Thromboembolism due to deep Venous Thrombosis due to Hypertensive and Arteriosclerotic Cardiovascular Disease

2006 Deaths Reviewed:

1. Colonizing Aspergillosis Complicating Chronic Granulomatous Pulmonary Disease
2. Mental Retardation with Seizure Disorder, Etiology Undetermined
3. Hypertensive Cardiovascular Disease
4. Primary Cerebellar Intraparenchymal Brain
5. Hemorrhage due to Hypertensive Cardiovascular Disease
6. Bronchopneumonia due to Acquired Immunodeficiency Syndrome

* Cause of death for cases with an asterisk were determined by jurisdictions other than the District of Columbia

GLOSSARY OF TERMS

	Definition
Age	The length of somebody's or something's existence: the length of time that somebody or something has existed, usually expressed in years
Autopsy Report	A detailed report consisting of the autopsy procedure, microscopic and laboratory findings, a list of diagnoses, and a summary of the case
Cause of Death	The underlying pathological condition or injury that initiates the chain of events which brings about the demise
Cerebral Palsy	An umbrella term encompassing a group of non-progressive, non-contagious neurological disorders that cause physical disability in human development , specifically movement and posture
CRF	Community Residential Facility for individuals diagnosed with an intellectual disability (MR)
Gender	The sex of a person or organism (male or female), or of a whole category of people or organisms
Group Home	Licensed homes for persons with mental retardation that range in size from four (4) to eight (8) customers
Hospice	A program or facilities that provide special care for people who are near the end of life and for their families
Hospital	An institution where people receive medical, surgical, or psychiatric treatment and nursing care
ICF/MR	A licensed residential facility, which is certified and funded through Title XIX (Medicaid) for consumers diagnosed with an intellectual disability (MR)
Leading Cause of Death	The largest number of deaths for all ages by cause.
Level of Disability	Cognitive and adaptive impairment ranging from mild to profound
Life Expectancy	The average expected length of life: the number of years that somebody can be expected to live
Manner of Death	Events surrounding the death
Mental Retardation	Below-average general and intellectual level of functioning
Natural Home	Consumers residing in the home of a parent, family members or independently
Neurologic Conditions	Disorders of the neuromuscular system: The central, peripheral, and autonomic nervous systems, the neuromuscular junction, and muscles

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Nursing Home	A long-term healthcare facility that provides full-time care and medical treatment for people who are unable to take care of themselves
Race	A distinct population of humans distinguished in some way from other humans. The most widely observed races are those based on skin color, facial features, ancestry, genetics , and national origin
Recommendations	A course of action to promote improvement in the delivery of care or services
Skilled Care	An institution (or a distinct part of an institution) that is primarily engaged in providing skilled nursing care and related services for residents who require medical or nursing care, or rehabilitation services for the rehabilitation of injured, disabled, or sick persons
Specialized Home Care	A private home living environment for three (3) or less individuals (also includes foster care)
Supervised Apartments	Typically a living arrangement for one to three customers with mental retardation, with drop-in twenty-four hour supervision. Supervised Apartments may be single units grouped in a cluster within an apartment complex, or scattered throughout a complex
Systemic Issues	Affecting the entire system of care and services rendered
Ward	A city division: an administrative or electoral division of an area such as a city, e.g., Wards 1-8 in the District of Columbia or Individuals under the custody and care of the District of Columbia.

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We wish to acknowledge the dedication and unwavering support of the public servants, private agency/program representatives, university, and community volunteers who serve as members of the District of Columbia Mental Retardation and Developmental Disabilities Fatality Review Committee. It is an act of courage to acknowledge that the deaths of individuals diagnosed with mental retardation and other developmental disabilities is a community problem. The willingness of Committee members to step outside of their traditional professional roles and examine all the circumstances that may have contributed to these deaths and to seriously consider ways to improve the quality of life and to prevent future fatalities is an admirable and difficult challenge. This challenge speaks to the commitment of members to improving services and truly making life better for the residents of this city. Without this level of dedication, the work of the Committee would not be possible.

We would like to thank the members of the Committee for volunteering your time, giving of your resources, support and dedication to achieving our common goal. A special thank you is extended to the community volunteers and educators who continue to serve the citizens of the District throughout every aspect of the fatality review process.